

Illness beliefs in schizophrenia

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Abstract

Beliefs about health and illness shape emotional responses to illness, health-related behaviour and relationships with health care providers in physical illness. Researchers are beginning to study the illness beliefs of people with psychosis, primarily using approaches developed in physical illness. It is likely that modifications to these models will be necessary if they are to apply to mental disorders, and it is probable that some of the assumptions underlying the models will be inappropriate. In particular, different dimensions of understanding may be present in mental illness in comparison to those identified in physical illness. The present study examined the beliefs of 20 patients diagnosed with schizophrenia, including 10 currently psychotic inpatients and 10 outpatients in remission, about their experiences, using qualitative interviews and thematic analysis. Patients currently experiencing psychosis did not identify their experiences as separable ‘illnesses’ and did not have ‘illness beliefs’. Patients currently in a period of remission appraised their experiences as distinct from their own normal behaviour, but used conceptual frameworks of understanding that deviated significantly from conventional ‘health belief’ models. Patients’ ways of understanding mental illness did not parallel those described in physical illnesses. Methods for assessing beliefs about mental illness should therefore not directly be transferred from studies of beliefs about physical illness, but should be tailored to the nature of patients’ beliefs about mental illness. (222 words)

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Introduction

Beliefs about health and illness shape our emotional responses to illness, our health-related behaviour and our relationships with health care providers (Salmon, 2002). Theoretical models such as the health belief model (Becker & Maimon, 1983) and self regulation theory (Leventhal, Nerenz & Steele, 1984) account for significant variance in health-related behaviours and have led to specific interventions to improve health outcomes (Petrie, Cameron, Ellis, Buick & Weinman, 2002).

Researchers are beginning to study the illness beliefs of people with mental disorders, using approaches developed in physical illness. Most researchers examining illness perceptions in mental health use (either explicitly or implicitly) models of illness belief drawn from physical health (e.g. Lobban et al 2004 and Haley et al 2003), although some exceptions must also be noted (e.g. Birchwood et al, 1993). This is consistent with the fundamental transdiagnostic or generic ethos of the health belief and self regulation models (Becker & Maimon, 1983; Leventhal, Nerenz & Steele, 1984) which certainly do not exclude mental health from their scope. Nevertheless, such models developed from the perspective of physical health and tend to make several assumptions that may not apply to mental health problems.

It is, therefore, commonly assumed that people possess relatively consistent sets of beliefs concerning their health and that these reflect underlying, relatively consistent 'models of illness'. Moreover, these models are generally focussed on beliefs of necessary interest to researchers, perhaps at the expense of issues of interest to patients. Thus, in physical health, these 'illness models' have focused on beliefs such as those concerning cause, course, nature, consequence and treatability.

Although some researchers have applied the theoretical frameworks and associated

methodologies that have been helpful in physical health problems to the study of patients' beliefs about mental ill health (Lobban, Barrowclough & Jones, 2003), it is likely that significant modifications to these models will be necessary. Thus Barrowclough and colleagues (2001) and Lobban and colleagues (2004) found that assessment measures based on Leventhal's 'Self Regulation Model' (Leventhal et.al., 1984) were useful but had limited applicability, and explained relatively little of the variance in key outcome variables.

There are, in fact, several reasons to be sceptical about a simple translation from physical to mental health. In psychological research in physical health, it is generally assumed that a person's beliefs about a particular condition are internally consistent and relatively stable, or that people strive for such coherent beliefs. Psychiatric patients, in contrast, may not have coherent beliefs about their ill health (Holzinger, Kilian, Lindenbach, Petscheleit & Angermeyer, 2003; Williams & Healy, 2001). In particular, people who have received a diagnosis of schizophrenia frequently experience severe conceptual disorganisation (or 'formal thought disorder') (Docherty, 2005). It is therefore possible that people with mental health problems will have beliefs about these problems that are particularly confused, inconsistent or contradictory, or that change with changes in the course of the psychological problems themselves.

Current conventional approaches to illness beliefs in physical health also suppose that the entity called an 'illness' can be appraised by an entity called the 'self' – that is, that people distinguish between the illness and themselves (Helman, 1994). This may be an assumption that is theoretically invalid in mental health, because the substrate that is affected by mental ill health is the self itself (Bentall, 2003; Brewin, 1996; Kinderman, 2005). Although core symptoms of hallucinations

and delusions are, by definition, not distinguished from the self, it is not clear whether patients distinguish a disease entity from themselves. Researchers have also explored the impact on recovery from mental disorder of styles of ‘integration’ (curiosity, openness and assimilation) and ‘sealing over’ (denial and repudiation) (McGlashan, Levy & Carpenter, 1975). These two differing appraisals of the disorder appear to influence the way in which a person is affected by their difficulties. On a related note, the concept of ‘insight’ pervades mental health care (Amador et al., 1991; Sevy et al., 2004) where it is commonly held that some patients (with more severe problems) are occasionally unaware that they are experiencing a mental illness. Clearly, the concept of ‘illness belief’ is an oddity if one does not believe that one is ill. In all these discussions, then, the simple concept of a patient as a dispassionate observer of internal processes may be invalid in the case of mental illness.

In the physical health domain there has been some discussion of whether other aspects of illness beliefs concerning culture, meaning and spirituality, and which are studied by approaches such as anthropology and qualitative methodology, may be more salient to patients than the beliefs studied using traditional psychological and quantitative methods (Salmon, 2000). It may well be the case that these issues are of particular importance in mental health. As with physical illness, patients may understand their problems in ways that differ substantially from dominant theoretical approaches.

Illness beliefs have social as well as psychological dimensions, in that they arise in social interactions concerning illnesses. There may therefore be important differences in the appraisal, by patients, of the use of illness labels in different contexts, such as socially, or by professionals in therapeutic encounters. In physical health, the use of illness labels by professionals to refer to an external disease entity

generally facilitates patients' transactions with doctors and others by removing or ameliorating moral implications (Helman, 1994). 'Disease' labels in mental health are much more controversial. Disease labels, rather than providing the basis for amoral communication as in physical health, may be very negatively, and very idiosyncratically, regarded by patients in psychiatric settings (Angermeyer & Matschinger, 2003; 2005; Farina et al, 1971; Mechanic et al, 1994; Warner et al, 1989).

This issue highlights the difficulties inherent within the therapeutic relationships between mental health professionals (particularly psychiatrists) and patients experiencing mental ill health. Colombo and colleagues (Colombo, Bendelow, Fulford & Williams, 2003) discussed the differing models of serious mental illness used by members of multi-disciplinary teams, including patients themselves. They reported that different members of the teams commonly used very different conceptual models of mental ill health: psychosocial versus medical, for instance. It cannot be comfortably assumed that an 'illness belief model' is appropriate to all.

The present study clarified and extended these possible conceptual differences. There are good reasons to suppose that conventional approaches to the investigation of illness beliefs extrapolated from physical illness may be inappropriate for mental ill health. These include doubts about both the existing methodological approaches, and the conceptual frameworks which underpin them. The present study is an investigation of the beliefs of patients diagnosed with schizophrenia using a qualitative methodology which allowed participants to describe how they think about their illness experiences. This study found features of these individuals' beliefs that

diverge strikingly from the assumptions that are made when illness beliefs are studied within the same framework as those concerning physical health.

Methods

Participants

Following local research ethics committee approval, 7 consultant psychiatrists in Liverpool (MerseyCare NHS Trust) were asked to refer patients with a diagnosis of schizophrenia and receiving in-patient or out-patient treatment for recruitment into a study of beliefs about mental health. Inclusion criteria were i) over 18, ii) English speakers and iii) diagnosis of schizophrenia (diagnoses were established in each case by the clinical team, rather than the researchers). Recruitment was, therefore, purposive, in seeking male and female patients across a wide age-range at different stages of their illness.

Potential participants were informed that this was a study of beliefs about mental health and that the interviewer was a research assistant under the supervision of a clinical psychologist. Altogether 30 patients were approached; 15 in-patients and 15 out-patients. Ten in-patients and 10 out-patients participated in interviews.

Participants were interviewed by one of the authors (ES), under supervision of the other authors who encompassed experience in clinical and research interviewing and in qualitative analysis. Access to the psychiatry records of participants was not requested. All in-patients were currently experiencing psychotic symptomatology (hallucinations, delusions or formal thought disorder) as assessed by ES and confirmed by the clinical team in charge of the patients' care. No formal psychiatric

assessment was made of participants in the out-patient sample, but all were confirmed by the clinical team in charge of the patients' care to be currently in a period of relative remission. Participants were excluded if they were judged by the clinical team or the researcher to be too distressed to participate in the study or if their problems were believed by the clinical team to be related to substance abuse or organic factors.

Interviews

The interviews were lightly structured using an interview guide, which listed key domains to be explored, including patients' beliefs about: the reasons that they entered psychiatric care; associated experiences; any illness labels, such as 'illness', 'schizophrenia' or 'depression', that they or others had applied to their problems; the effects and mode of action of treatments they had been offered. However, because questioning was responsive to the participants' own comments and situation, the order in which issues were addressed and the allocation of time to them varied between interviews. Patients dictated the pace and sequencing of interviews. The interviewer emphasized her independence from the clinical team, avoided closed questions except where necessary to pursue specific points, and encouraged patients to talk in their own ways about their mental health and the experiences that brought them into hospital. The interviews varied in length from 10 to 40 minutes.

In order for the interviewer to pay full attention to the participants' accounts and to provide verbatim transcripts for subsequent analysis, participants were asked to consent to audio recording. Eighteen of the 20 interviews were audio-recorded and transcribed. Data from the remaining 2 interviews were included in analysis, based on verbatim notes written by the interviewer during and immediately after the interview.

Analysis of interview transcripts

Analysis followed procedures that we have used previously in qualitative studies of patients' illness beliefs (Peters et al, 1997). Analysis was inductive and followed established conventions for ensuring that it was grounded in data rather than reflecting pre-existing ideas (Dey, 1993; Patton, 1990). Analysis was conducted in parallel with data-collection so that aspects of the developing analysis could be tested and developed in subsequent interviews. After preliminary reading of four transcripts and discussion by all authors, a categorisation and thematic analysis was developed by 'cycling' between the analysis and those transcripts and periodic 'testing' of the analysis by discussion amongst the entire team so as to meet accepted standards for trustworthiness of the analysis (Patton, 1990; Stiles, 1993). Data collection continued and the analysis was modified accordingly, until no further modifications emerged and all relevant text could be codified.

The importance of cross referral between the data and the developing analysis, and the use of different authors in different roles, is widely recognized (Mays & Pope, 1995; Stiles, 1993). In addition, key standards of validity for our purposes included coherence of the final analysis (Stiles, 1993), its ability to account for all relevant data, its 'theoretical validity' whereby it should connect with wider theoretical ideas, and so called catalytic validity (Guba & Lincoln, 1989), which is essentially the utility of the analysis in identifying implications for clinical practice and research that can be tested.

Results

Characteristics of participants

The median age of the participants was 39 (range 22 to 58). The median age of

the inpatient sample was 35.5 (range 22 to 40), the median age of the outpatient sample was 44 (range 33 to 58). All but two participants described themselves as White British, with one describing himself as Asian British and one as Chinese British. Sixteen of the 20 participants were male; eight each in the inpatient and outpatient groups. It is possible that some of the in-patient sample were subject to compulsory detention (this was not an exclusion criterion), but this information was not directly relevant to the research questions and therefore was not recorded for reasons of confidentiality.

Narrative themes

Reading of the first transcripts indicated important differences between the inpatient and outpatient groups. Further analysis therefore continued to contrast these groups, which are discussed separately below.

Inpatient sample

On initial reading, the transcripts were confusing and appeared to defy coding in respect of beliefs. The relationship between this observation and the twin issues of conceptual disorganization and ‘insight’ will be discussed below. However, continued reading and discussion suggested that our difficulty reflected the fact that the participants’ accounts did not accord with assumptions that, although rarely made explicit, conventionally underlie the psychological study of health beliefs. Specifically, we questioned the assumptions that patients distinguish an illness entity from their view of themselves and that they have coherent belief systems about this illness. Further, because patients did not separate illnesses from themselves, we were led to consider the moral and social aspects of their beliefs about their experiences

related to schizophrenia.

We identified three key characteristics of inpatients' understanding: their experiences were inseparable from their identity and other life experiences; beliefs were flexible and uncertain; and the acceptability of labels of and explanations for illness depended on who was applying them (Table 1). Each characteristic is defined and illustrated below.

TABLE 1 about here

The inseparability of illness from patients' identity

Participants did not separate the problems and experiences that related to their diagnosis of schizophrenia from other aspects of their lives. No participant spoke from a dispassionate stance, scrutinising an external 'disease entity'. Patients' accounts therefore linked their problems seamlessly with spiritual and moral issues, and indicated that the problems were part of their sense of self.

Inpatient 6: *"It is just a very strong spirit. I felt connected completely, with the universe, with the Cosmos or whatever you want to call it. With who I am, why I am here."*

Indeed, some were explicit that their illness was integral to the self; i.e. that the psychotic experiences were fundamental to their identity.

Inpatient 6: *“The aspect of who I am, the illness it’s me, as much as.”*

Therefore, patients’ accounts of their experiences that were related to the diagnosis of schizophrenia extended through the whole of their lives. Many reported a sense of loss of identity, but also a struggle to integrate the psychotic experiences with other aspects of life. In particular, illness experiences were often described in a moral way – as punishment or as unfair.

Inpatient 5: *“I think that’s why I hear voices. Like a punishment. That’s why I say that there is a god.”*

Inpatient 2: *“I was a number to them, I wasn’t a person, I was piece of shit.”*

Similarly, some patients linked illness experiences to a sense of purpose, and of having a mission in life.

Inpatient 2: *“I got ill for the glory of God.”*

The flexibility and uncertainty of beliefs

There was little evidence of coherent and consistent ‘illness models’. Instead, patients’ accounts were fluid and changeable. Instead of clear beliefs, patients described doubts and questions. Indeed, many were explicit that they were confused, and trying to work out what was happening. In the interview below, a closed question explicitly addressed this issue following more protracted open-ended questioning).

Inpatient 3: Interviewer: *“So, what would you say? Would you say are voices*

real or are part of the illness?” Patient: “I can’t distinguish; I can’t tell.

That’s what hurts me.”

Inpatient 8: “I don’t know I’m not a professional am I? I don’t understand what’s going on with me. I mean doctors have said it could be childhood, regression, it could be illegal drugs, but I’ve never taken illegal drugs.”

Participants were also able to hold apparently disparate beliefs simultaneously. In particular, they used scientific and spiritual frameworks interchangeably, did not regard these as inconsistent and did not link them, for example by indicating common mechanisms or by establishing dominance of one over the other.

Inpatient 9: “I’ve seen programmes on television about electromagnetic radiation and electromagnetic pollution, and it could be something to do with lights, you know the mains frequency? ... Could be radio signals ... it could have been a spacecraft, couldn’t it?”

Inpatient 9: “I want to take medicines to stop me to go high. I recognise the problem and ... that you need to control it. ...It is just like, some kind of manic energy stored up, that has not been used. ... It’s like you have to believe in something deeper beyond yourself, you know, like, - why we’re here.”

The social dimensions of illness labels

Many participants used illness terms to refer to themselves and their problems. However, these labels appeared to have a different meaning when used by the patients themselves and when used by the interviewer. Illness terms used by the interviewer

were frequently rejected, even when the participant had used similar terms.

Inpatient 8: *"Look it's a very complicated illness right, it affects the brain.*

Interviewer: *"Oh Right, Okay. So I just don't know what you think about the*

voices, do you think that they're part of the illness?" Patient: *"It's not an*

illness, How can you say it's an illness?" Interviewer: *"So, if you say that*

schizophrenia is not the right word for you, what would you say is?" Patient:

"I think I'm mad."

In addition, participants used such common labels as 'schizophrenia', 'depression' and 'stress' in personal and idiosyncratic ways.

Inpatient 3: P: *"Well, Dr W_ thinks I am schizophrenic."* Interviewer: *"What*

do you think?" Patient: *"What do I think?"* Interviewer: *"Yes"* Patient: *"I*

don't know. I know there is something definitely wrong with me, but, I don't

know if it is schizophrenia, I don't know. I think it could be. I don't think it is

severe schizophrenia. I think is on the border. I think some people in here are

a lot more ill than me. I think it is border schizophrenia."

Outpatient sample

Like the inpatients, outpatients also integrated illness into their accounts of their lives. However, the way that they did this differed consistently from the inpatients in that they distinguished their illness experiences from their current selves. That is, whereas inpatients described experiences related to their illness as part of their current identity, the outpatients identified those experiences as separate from

themselves. Therefore, from the vantage-point of their current selves, they could appraise those experiences (Table 2).

TABLE 2 about here

Patients' separation of current self from past experiences

Whereas the inpatients consistently did not provide coherent 'beliefs' about their experiences related to their diagnosis, the outpatient group consistently did so. They distinguished their recalled experiences from their current selves and scrutinised them from the perspective of their current selves as events to be appraised and discussed. However, they did not describe themselves as agents managing their experiences, but as spectators on their experiences and surrounding events.

Patients most commonly achieved separation from their experiences by presenting them as episodes, temporally distinct from their current life. Participants contrasted their behaviour, thoughts and experiences during those episodes with their current and premorbid life.

Outpatient 3: *"Also at the time I was hearing voices and I couldn't stop walking because otherwise I would have got shot, so I kept walking."*

Outpatient 15: *"I was in the park and I took my clothes off and the police got me, I just wanted to get noticed."*

Patients defined the episodes as periods when they were out of touch with

reality, in contrast to their current selves which were real and therefore a valid perspective from which to describe their experiences in terms of unreality – hearing or believing things that, from the perspective of their current selves, were ‘untrue’ or ‘false’.

Outpatient 15: *“I’m beginning not to believe it now, about the horses, you know. I tried to do it again on TV and I’ve realised that the jockeys don’t look at the camera, so I can’t tell them to run faster.”*

Outpatient 18: *“So I was making these false connections all the time. I remember sometimes I was saying to my self this can’t be right, but I wasn’t able to control them.”*

Illness labels

Although the outpatients did not, therefore, describe an external illness entity, many described themselves as having been ‘ill’, and referred to the illness as an ‘it’.

Outpatient 12: *“Yes, it was affecting my self-esteem, my confidence, my relationships, not only with my husband, but also with everybody.”*

Outpatient 13: *“I think it was the cannabis that triggered it all.”*

Many, moreover, freely used diagnostic terms, particularly the term ‘schizophrenia’. The labels were sometimes presented as ones applied by other people and sometimes as ones adopted by the patients.

Outpatient 4: Interviewer *“So, what was the diagnosis they gave you here?”*

Patient: *“I don’t know, schizophrenic.”* Interviewer: *“What do you think it is?”* Patient: *“I don’t know. I think, I don’t know, I just see things, I can’t explain.”*

Outpatient 5: Interviewer: *“What do you think about the diagnosis of schizophrenia?”* Patient: *“I bought a magazine, about minerals and vitamins, I even took primrose and it said it’s for schizophrenia. Also on TV people suffering from schizophrenia and I found myself crying because it reminded me of myself years ago.”*

However, in contrast to the inpatient sample, these labels had strikingly little moral, evaluative or other significance. That is, participants did not describe hostility, fear or enthusiasm about the labels, regardless of who applied them.

The social and psychological elements of illness labels

Whether or not patients used an illness label, many went on to provide complex accounts of their illness. None made simple attributions to medical, psychological or social factors. Instead, their accounts included a mixture of physical, social and psychological influences and experiences. The most common account implied an interaction between personal characteristics (cast in terms of vulnerability) and psychosocial stresses.

Outpatient 2: *“I was really stressed. My partner ... didn’t do anything to help, he just avoided me and so I started to think he was cheating on me with other*

women. ... *I think, he was making me ill, with all the stress and everything. I felt like I had a brain tumour.*”

Several patients specified stressful social experiences, in particular abuse. However, emotional and moral language, such as anger or references to punishment or deservingness, seen in the inpatient sample, was absent. Patients’ experience of events was described passively or intellectually rather than emotively, even when potentially emotive topics were described.

Outpatient 18: Interviewer: *“Do you know why [the problems began]?”*

Patient: *“No, I don’t know for certain. I had taken some pot before my first admission and I thought somebody might have dropped some acid on it. I also had a difficult childhood. I was physically and emotionally abused, sexually abused as well. This is very difficult for me to get my head round.”*

Similarly, the language of purpose, specialness and mission that was seen in inpatients was absent. Participants therefore referred to the possible origins of their problems, their social and personal impact and the issues surrounding the labels used with apparent passivity.

Outpatient 18: Patient: *“I started to hear voices, but they were not nice voices, they were horrible.”* Interviewer: *“Did you recognise them?”* Patient: *“It was the man that abused me ...I met this man that was a builder, in construction, you know? And he said that he wanted to give me a job, but they were all lies, he was trying to con me. He took me back to his house, he locked the door and*

he had sex with me. ... And then other voices as well. I went to ... hospital and the nurses were very good to me.” Interviewer: “When you went to hospital what did they say it was wrong with you?” Patient: “Schizophrenia, paranoid schizophrenia.” Interviewer: “What do you think personally?” Interviewer: “What do you mean?” Patient: “Do you think it is what you’ve got?” Patient: “Oh yes, that’s what I have got.”

Hopelessness and resignation

Indeed, the absence of the personal agency seen in patients’ accounts of social adversities, above, pervaded the outpatients’ accounts. The language of hope, struggle and puzzlement that the inpatients freely used was absent. Instead, they were fatalistic, displaying no sense of agency or motivation concerning their lives.

Outpatient 4: Interviewer: *“So, how do you see your future?”* Patient: *“I don’t see it. I don’t think about it.”* ... Interviewer: *“So, going back to the future, what’s next for you?”* Patient: *“I don’t see nothing.”*

Outpatient 5: I: *“So, how do you see yourself in the future?”* Patient: *“I don’t know. I don’t know where I am going through in life. I don’t have any plan. I look at the football on TV and horse racing....”*

Discussion

Researchers are beginning to study the illness beliefs of people with schizophrenia, using approaches developed in physical illness. Lobban and colleagues

(Lobban, Barrowclough & Jones, 2003) concluded that, while models of illness that have been helpful in physical health problems may be usefully applied to mental illness, it is likely that modifications to these models will be necessary. In particular, they felt that different dimensions of understanding may be present in mental illness in comparison to those identified in physical illness.

The present study clarified and extended these possible conceptual differences. A qualitative methodology allowed patients diagnosed with schizophrenia to describe how they think about their illness experiences, and found features of their beliefs that diverge fundamentally from the assumptions that are made when illness beliefs are studied within the same framework as those concerning physical health.

Illness and identity

People who were currently experiencing psychotic phenomena did not separate a disease entity from themselves. Experiences regarded as ‘psychotic’ and as ‘symptoms of illness’ within medical conceptualizations were described by participants who were currently experiencing them as part of themselves and their lives. This contrasts with conventional psychological accounts of ‘illness’, which are predicated on the assumption that people distinguish between the illness and themselves (Helman, 1994). That is, even where illnesses are not associated with any distinguishable pathophysiology, such as high blood pressure or chronic fatigue, the illness is regarded as external to the self (Blaxter, 1983). From that perspective, it is natural to consider how the individual appraises the disease entity. That is, while it would be odd to consider how someone ‘appraises’ malignant proliferation of cells or feeling weary, it is regarded as natural to consider their appraisal of, or coping with, cancer or fatigue (Salmon and Hall, 2003).

The use of illness labels to refer to an external disease entity generally facilitates patients' transactions with doctors and others by removing or ameliorating moral implications (Helman, 1994). Limitations in a person's functioning, experience, or behaviour are blamed on the illness rather than the patient. Inpatients in the present study freely applied illness labels, typically 'schizophrenia' or being 'ill' to themselves. Moreover, their ownership of the labels was seen in their adaptation of them into idiosyncratic terms, such as 'border schizophrenia'. However, illness labels were rejected when applied by others, including the interviewer. It seems that, when used by others, these labels can be moral assaults. Therefore, for inpatients, disease labels did not provide the basis for amoral communication that they provide in physical illness.

Outpatients, who were not currently experiencing psychosis, used the language of illness – referring to “schizophrenic” and “making me ill” – but in a way that contrasted with the assumptions of physical illness belief models. Although outpatients separated their psychotic experiences from their current selves, and recognized that previous episodes of psychosis requiring hospital care reflected a contrast with normality, their accounts were characterized by a temporal rather than conceptual or diagnostic separation. Patients used forms of description that did not reflect external disease entities but, rather, described psychotic episodes as periods of socially recognized states of altered psychological functioning. This seemed most similar to describing a romantic adolescent crush “that was clearly me, but I was foolish, irrational and in love”. Thus, outpatients referred back to periods in their lives when their functioning was clearly both different and problematic – and acknowledged as such by themselves and by others. They (to differing extents) acknowledged both the irrationality exhibited during these periods, and (again to

differing extents) acknowledged the benefits of appropriate help. But, rather than discussing these problems as the product of an illness occurring in episodic form and extrinsic to the self, the participants discussed their own actions and thoughts. These actions and thoughts were dysfunctional and problematic, but remained their own rather than the emergent properties of an illness entity.

Therefore, for this group also, the validity of applying a concept of ‘illness belief’ taken from physical health is questionable. Although they can distance themselves sufficiently from a psychotic episode to appraise it, they do this in a way that does not entail appraisal of an exogenous illness entity.

Conceptual disorganization and ‘insight’

As outlined in the introduction, people experiencing psychosis are also frequently regarded as experiencing severe conceptual disorganisation (Docherty, 2005). They are also said frequently to lack ‘insight’ into their problems (Amador et.al., 1991; Sevy et al., 2004). Clearly both these issues might be thought to affect the quality and nature of participants’ responses. However, qualitative research has been advocated as a way of exploring the phenomena of both insight and thought disorder (Amador & David, 1998) and, in the present study, this approach was vindicated by the theoretically significant characteristics of respondents’ accounts that were identified by the analysis.

Whereas descriptions such as ‘thought disorder’, ‘conceptual disorganisation’ or ‘lack of insight’ interpret patients’ behaviour from the perspective of the professional observer, the importance of our qualitative approach is that it sought to understand patients’ experience from their own perspective. From this perspective, the fluidity of patients’ beliefs could not be described adequately as disorganisation, but

bore some resemblance to that described previously in relation to depression (Williams & Healy, 2001) and unexplained physical symptoms (Peters et al, 1997), whereby patients entertained disparate and changing explanatory frameworks in the struggle to make sense of their experiences.

Similarly, while it might be argued that patients' integration of self and illness is a product of the lack of insight traditionally identified with psychosis this would, again, be to assert a professional perspective. Moreover, it privileges a specifically psychiatric perspective. Psychological accounts of 'insight' do not adopt such a straightforward assumption that a particular (medical) perspective is correct. Since there are many valid models of psychological distress (Colombo, Bendelow, Fulford & Williams, 2003), there can be no presumption that acceptance or rejection of any one perspective is preferable or 'insightful'. From the perspective of the present study, therefore, patients in each group neither lacked nor possessed 'insight'. They gave meaningful accounts of their difficulties in terms of personal history rather than illness. It may well be that building upon the willingness or ability of a person to accept that they have acted differently during a past episode of psychotic experiences, compared to their 'normal' behaviour, would allow that person to engage with services to prevent or mitigate such problems in the future (British Psychological Society, 2000; McGlashan & Carpenter, 1981). This provides a potentially different basis for therapeutic collaboration from that normally involved in taking a cognitive-behavioural approach.

Theoretical implications

The findings of the present study have important theoretical implications. Disputes about whether schizophrenia "has been clearly established to be a brain

disease” (Torrey, 1988 p73) or alternatively not an illness in any sense of the word (Bentall, 2003) are notorious in psychiatry. This study cannot answer that issue directly, but indicates what this sample of patients thought about the nature of their psychotic experiences. Participants were able to look back on periods of psychosis, but appraised these as periods of altered rationality. Their discourses differed in a number of respects from discourses of physical illness.

Participants in the current study did not describe their experiences as resembling conventional physical illnesses. Although participants did use the language of illness, this should not deceive us into thinking that, by accepting the practical utility of discussing ‘illness’, patients mean what researchers or clinicians tend to think they mean.

Colombo and colleagues (Colombo, Bendelow, Fulford & Williams, 2003) discussed the differing models of serious mental illness used by members of multi-disciplinary teams, including patients themselves. They reported that different members of the teams commonly used very different conceptual models of mental ill health: psychosocial versus medical, for instance. Colombo and colleagues further reported that, while some patients accepted and used a bio-medical model of mental ill health and therefore resembled, in that respect, traditional psychiatrists, others adopted a psychosocial model and more closely resembled social workers. The results of the present study both reflect these findings and extend them. It is clear that people who have received a diagnosis of schizophrenia frequently use conceptual frameworks of their experiences that fail to resemble a conventional ‘illness’ model, but, equally, our findings indicate that they can fail to adopt a conventional social or psychological model. The findings of the present study cast the person experiencing psychological problems as an actor in their own life’s drama, rather than as a vector of

illness.

The concept of ‘recovery models’ in mental ill health offers new opportunities for optimism for patients (Warner, 2003). However, it was striking that the participants in the present study did not see themselves on any form of road to recovery. They had no coherent view of what had happened, was happening and would happen. One important area of utility for illness belief models is in their applicability to recovery (Petrie et al., 1996; Horne et al., 2000), because the beliefs that patients hold about their difficulties are a powerful influence on affect and behaviour. The findings of this study suggest that the available ‘illness belief’ models used to conceptualize mental ill health are inappropriate or inadequate. Participants in the present study, moreover, were demoralized and lacked a sense of possible ‘recovery’. Although speculative, it may be the case that a model of ‘recovery’ based on patients’ conceptualization of psychosis as episodes of irrationality within their life history could offer advantages. Such a model seems to fit well with the participants’ framework of understanding of their difficulties.

Limitations

Several limitations of the present study must be recognized. As a qualitative study, the findings cannot be generalized. Nevertheless, the importance of qualitative work in health care is often to challenge views that have been taken as evident in the absence of the necessary evidence. Our finding that illness beliefs in psychosis fail to map onto key assumptions of conventional illness belief models should therefore prompt more extensive research to test and develop the ideas described here.

Samples in work such as this are necessarily subject to clinician- and self-selection. In both in-patient and out-patient samples, participants who were relatively

more cooperative were, of course, more likely to participate. Nevertheless, participants reflected a relative uncertainty and flexibility in illness representations rather than a settled view, and did not recite a conventional, medical, approach to their problems. In both cases, the opposite would have been expected if especially compliant participants had been favoured. Given the highly heterogeneous nature of psychotic phenomena (Bentall, 2003), similar research in other samples is necessary. Details of symptomatology, which we did not assess formally, could help inform comparison of findings from the patients' perspective with their psychiatric characteristics. Knowledge of patients' education might help in interpreting the language used.

Practical and clinical implications

The findings of the present study extend the conclusions of Lobban, Barrowclough and Jones (2003) and Talley (1999), who suggested that psychiatric patients do form cognitive representations about their experiences, but that it may be inappropriate to use methods derived from physical health to assess these beliefs. The present findings suggest that different ways of understanding may be present in mental illness in comparison to those identified in physical illness. First, in patients who are currently experiencing psychotic episodes, the concept of illness belief is invalid because they have no concept of illness. Secondly, outpatients' readiness to use the familiar language of illness belies a concept of illness – as an episodic deviation from the current self – that diverges fundamentally from the assumption of the health-belief literature that illness is perceived as a distinct and continuing entity.

This does not mean that one cannot use standard questionnaires (such as the Illness Perceptions Questionnaire; Weinman, Petrie, Moss-Morris & Horne, 1996),

which have been extensively used in assessing illness beliefs in physical illness, to explore beliefs about mental illness. Indeed, the IPQ has been used in such research (Barrowclough, Lobban, Hatton & Quinn, 2001; Lobban et al, 2004). Rather, it suggests that, by using the methodologies developed using structured questionnaires based upon theoretical structures concerning physical illness beliefs, such assessments may not reflect validly how people think about psychosis. Further research is required to examine the appropriateness and applicability of quantitative methods of assessment based on the present findings.

Clinically, the present study highlights the difficulties inherent within the therapeutic relationships between mental health professionals (particularly psychiatrists) and patients experiencing psychosis. The present findings suggest that it may be both impossible and invalid to discuss with patients what they believe “about their illness”. Clearly, patients have very distressing problems. But they do not attribute these problems to an ‘illness’. Moreover, partly because of this, many disease labels are experienced as challenging to their sense of self. In consequence, many patients react to such illness labels with hostility. Moreover, even when patients do use the language of conventional illness, the present study indicates that dialogue may be compromised by the fact that patients mean in their use of these terms something different from that meant by professionals when using exactly the same words.

The present study does, however, offer hope. Outpatients discussed their experiences – the ‘symptoms of illness’ – in terms of episodes of irrationality. These episodes were located in their broader lives and experiences. The episodes of irrationality were discussed in terms of causes and consequences, and helpful and less helpful responses by the patients and by professionals were appraised. Patients’

models of illness as episodes of irrationality may therefore offer a basis for more effective dialogue with patients about the cause and course of their illness.

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Table 1: Properties of the beliefs of the inpatient sample

The inseparability of illness from patients' identity

- psychotic problems inseparable from the patients' wider lives, sense of self and spiritual and moral issues
- psychosis not appraised as a 'thing' apart from the appraiser

The flexibility and uncertainty of beliefs

- absence of consolidated 'models' of illness in acute psychosis
- inconsistent and fluid beliefs about psychotic problems
- puzzlement and confusion

The social dimensions of illness labels

- patients have a strong tendency to own the use of labels such as 'psychotic' and 'schizophrenia'
- such labels experienced as statements about the individual and with moral as well as descriptive significance
- models and labels concerning psychotic problems are commonly experienced as pejorative

Table 2: Properties of beliefs of the outpatient sample

Patients' separation of current self from past experiences

- 'illness models' discernable during periods of relative remission
- periods of psychosis viewed as autobiographical episodes
- psychosis described as a state of detachment from reality

Illness labels

- labels such as 'psychotic' and 'schizophrenia' remain perceived as statements about the individual
- models and labels concerning psychotic problems are commonly pejorative

The social and psychological elements of illness labels

- discussion of 'illness', but also psychosocial stress, morality and spirituality
- accounts of past psychotic experiences enmeshed in other aspects of the patients' lives and part of the sense of self
- integration of physical, social and other approaches implied and idiosyncratic.

Hopelessness and resignation

- unremitting hopelessness
- resignation and a lack of personal agency